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ABSTRACT

Existing patterns of deinstitutionalization and group home placements funded through Supplemental Security Income (SSI) and private supplemental trusts can provide the means for independent living for developmentally disabled adults. Yet, because of the propensity of probate courts to refrain from alteration of written documents evidencing the intent of the settlors of estates, innocent mistakes made by parents in their estate plans can have devastating impact upon the surviving developmentally disabled child and other family members. In most cases, the primary goal of the estate planner must be to protect SSI eligibility. This article is intended to provide information to the estate planner concerning the SSI program and related estate planning issues centering on the segregation and management of funds for the developmentally disabled child. SSI eligibility criteria are cited, restrictions on the establishment of trusts are set forth, and the role of family members as co-trustees is discussed. (JW)

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Special Considerations for Special People

Estate Planning for Families with a Developmentally Disabled Child

By Joel S. Welber

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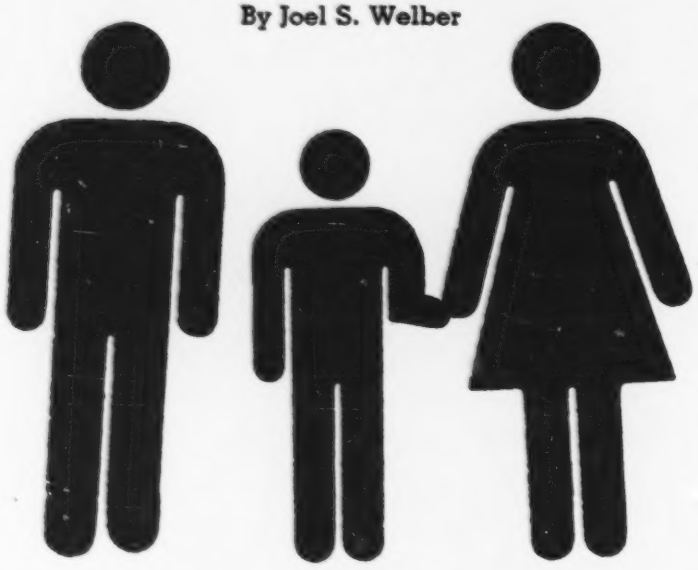

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Parents of the developmentally disabled[1] have historically struggled with the question of what will happen to the child[2] upon their deaths. Typically, parents would maintain their handicapped child in the family residence for as long as possible, and then either place the child in a state institution or with relatives.[3] But neither alternative held forth much hope of a happy and comfortable future for the child.

Institutionalization was broadly feared by parents who had given their child devoted, individualized attention for many years in the home. Physical and/or emotional abuse, coupled with a depersonalized living environment stereotyped the institution as an alternative to be avoided.

Placement with relatives was perceived as an unfair imposition on the relatives' time, patience, and resources. Clearly, this perception corresponded with reality in the majority of cases. The degree of imposition increased with the severity of the disability. (Maintenance of the developmentally disabled child in the family residence with outside support by way of contract labor has been virtually abandoned as logistically and economically impractical upon close scrutiny).

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Within the past decade, this planning dilemma has been virtually resolved with the emergence of group-home living as the life style of the future and the corresponding deinstitutionalization of this state's developmentally disabled population.[4] Small group homes provide an economically superior alternative to the cumbersome state institution (for the state)[5] as well as represent a promising environment for individual growth in a comfortable and humane setting.

During this continuing period of deinstitutionalization, many of the parents of the developmentally disabled have developed an increased awareness of the need for careful estate planning. Once the general question of where an offspring will be placed is resolved, parents inevitably focus on the fiscal question of how the placement will be financed and perpetuated. This article will discuss the financial aspects of such estate planning.

Practitioners must become aware of the existence of federal and state entitlement programs as the primary source of group-home placement funding, and those planning techniques which are essential to maintaining eligibility for the clients' child. Attorneys, as planners, must also realize that proper eligibility protection may enable parents to allocate resources fairly among all offspring, while insuring maximum potential development for the handicapped child.

Retain SSI Eligibility

In an overwhelming majority of cases, the primary goal of the estate planner must be to protect "SSI" eligibility for the developmentally disabled child.[6] The Supplemental Security Income (SSI) Program is designed to provide a guaranteed annual income to the disabled.[7] SSI is a federally funded program administered by the states.[8]

The program provides payments for shelter, food, and incidental expenses on a monthly basis.[9] (Incidental expenses might include clothing, recreational and leisure time expenses and small items of personal property). The program dovetails with Social Security to provide a combined benefit to a maximum allotment.[10]

Most group homes establish the SSI payment as the amount charged for room and board to a resident as a matter of the home operator's budget. In other words, SSI is designed to — and does in fact provide — the basic life support ▶

needs for the developmentally disabled person living away from his or her family.[11]

In addition, SSI eligibility is generally accompanied by eligibility for MEDICAID, which is established by each state in partnership with the federal government and is administered by the state with reference to federal guidelines.[12] MEDICAID eligibility is extremely valuable to the developmentally disabled who are often afflicted with related physical disabilities or health problems of a serious nature. MEDICAID is substantially different from MEDICARE in both the amount of coverage that it provides as well as in the types of services that it covers.[13]

MEDICAID as a resource for the developmentally disabled has been called "the best health insurance package money can't buy." SSI coupled with MEDICAID is generally regarded as the basic fiscal resource available for the developmentally disabled person in the absence of his or her parents.[16] The literature on this subject is virtually unanimous concerning the need to protect SSI eligibility.

Eligibility Criteria

Both SSI and MEDICAID are available only to persons who meet rigid eligibility requirements; they are entitlement or assistance programs. Since SSI eligibility assumes the MEDICAID component and conversely SSI ineligibility implies MEDICAID ineligibility, the planner must understand the fundamentals of eligibility for SSI.

SSI has a two-prong test for eligibility once the disability is established. The applicant may have neither available resources nor income beyond prescribed amounts and still qualify to receive established benefit levels. There are well-formulated rules which are applied by the Social Security personnel to document or verify whether or not a particular applicant qualifies as a matter of fact under each prong of the resource-income test. These rules are published by the U.S. Department of Health and Human Services (Social Security Administration) and any detailed analysis of their contents would be well beyond the scope of this discussion.

The "available resource" test and the income criteria do, however, warrant consideration. The estate planner will be structuring the estate so that the developmentally disabled heir or beneficiary of an inter-vivos instrument will qualify under each of these tests:

> **In order to receive cash assistance under title XVI of the Act, an individual or a couple must satisfy certain eligibility requirements. One of those requirements is a limit on the value of resources an individual or a couple can retain and still receive Supplemental Security Income (SSI) payments. *The Act prescribes that countable resources for an individual or a couple must not exceed $1,500 or $2,250, respectively.* A countable resource is a resource which is not excluded by the Act or by another law. (see SI 01110.030).17 (emphasis added).**
>
> **Resources are generally defined as those assets including both real (SI 01130.305) and personal property (see SI 01130.500) which an individual or couple owns and can apply, either directly or by sale or conversion to meet basic needs or food, clothing, and shelter. Resources include all liquid assets which are held singly, or in joint names which can be accessed by the applicant (e.g., bank accounts, savings accounts, etc.). They also include all assets which are real or personal property (e.g., automobile, land equipment, etc.). See SI 01110.020 for a discussion of when receipt of resources may become income.[18]**

In determining whether or not the applicant has liquid resources in excess of the established ceilings, certain resources are exempt from consideration. These include an individual's home and within limitations, certain items of household goods, personal effects, an automobile and other property necessary to the individual's means of self-support.[19] As a practical matter, the planner should consider the use of exemptions to provide the applicant with small items of personal value, but for little else.

The homestead exclusion might be useful if the applicant is married. However, if this is not true or probable, the likelihood of the applicant actually living in the home upon his or her parent's death is very small. Therefore, a plan which ignores this reality is almost certain to result in the liquidated value of the home becoming a disqualifying resource at some point in the future.

With regard to income, SSI eligibility and payment levels consider not only earned income but certain types of unearned income as well. Income, per se, does not disqualify an otherwise disabled applicant from establishing eligibility, but rather, with certain exclusions, reduces the SSI payment in direct correlation with the amount of income received.[20]

Income is defined generally as: "the receipt by an individual of any property or service which he can apply, either directly or by sale or conversion, to meeting his basic needs for food, clothing, and shelter."[21] An applicant who receives free room and or board, or is provided with clothing, for example, receives "income" as provided by SSI regulation. An applicant or recipient living in his parents' home and receiving free room and board will have his or her payment reduced by a factor of one-third.[22]

Both the income and assets tests are continuous in nature. An SSI recipient will be disqualified if, for example, he or she fails the available resource test due to the availability of too many assets. The ineligibility will continue until the disqualifying available resources are exhausted. (With SSI eligibility destroyed, MEDICAID eligibility ceases, thus leaving the developmentally disabled person in a potentially precarious state). The reapplication process may be time consuming even after the disqualifying assets are consumed. This further jeopardizes the basic shelter, food, and clothing provisions for the individual.[23]

Planning Ahead: The Trust — A Basic Tool

Between 1973–1978, attorneys who knew about SSI regularly advised their clients to "disinherit" the developmentaly disabled offspring in order to protect SSI eligibility. Often parents would direct a minimum bequest (less than $1500) to the handicapped child with the balance of the estate going to other family members or elsewhere. (Many of these estate plans remain in place today and, in the opinion of this author, should be reviewed). Typically, parents would employ "side-agreements" with the "normal" child(ren) to assure that the "normal" child(ren) would allocate a portion of his or her inheritance for the comfort of the handicapped child.

Fortunately, disinheritance is no longer necessary to protect SSI eligibility. Social Security regulations now provide, in substance, that a beneficiary des-

ignation under a discretionary spendthrift trust is not deemed to be an available asset (resource) in the determination of SSI eligibility.[24] Parents can therefore establish an inter-vivos or testamentary trust as a source of additional resources for the developmentally disabled child. It is critical, however, that certain restrictions *must* be strictly adhered to in the drafting of the trust if the trust is to achieve the desired result:

1. The trust must *not* be established to provide resources for the support and/or maintenance of the developmentally disabled child;[25]

2. The developmentally disabled beneficiary must have *no* established or discretionary access to the income or the corpus of the trust in his or her own right;

3. The developmentally disabled beneficiary must have no right to receive the income as earned or on a regular basis; (the Trustee must have the discretion with regard to expenditures but no power to expend for support/maintenance).[26]

Notwithstanding these restrictions, the trust can be an extremely useful tool in achieving its actual goal. It provides funding for those needs that are not otherwise purchased by SSI or MEDICAID or any other related or similar program. Typically, these needs will include additional clothing, regular dental checkups and care, travel, small items of personal property (e.g., a television, radio), purchases of exempt assets, gifts for friends at holidays, programming services (e.g., social work evaluations on a regular basis), extraordinary expenses (e.g., legal advice), and similar amenities.

The trust document must be rather specific in directing the trustee in the avoidance of disqualifying expenditures and should contain the suggestions of appropriate expenditures. It must under any circumstances contain a restriction with respect to expenditures for support and welfare of the beneficiary.

Sample language reads as follows:

> **My trustee shall, in its sole and uncontrolled discretion expend so much of the income and principal of this trust for the comfort and well-being of our daughter/son, (insert name), including but not limited to the purchase of clothing, furnishings, or to provide expenses for travel, entertainment, periodic evaluation of the living conditions of our son by the trustee or consultants hired by the trustee, regular dental care and such other amenities as are not available to our daughter/son from any other source, and as it deems in her/his best interest.**
>
> **It is my express intention that these funds shall not be used for the support and maintenance of our daughter/son as these needs are already being provided.**

In a more general sense, the allotment of part of the parents' estate to a trust for the developmentally disabled offspring is designed to insure that the handicapped beneficiary has the opportunity to achieve his or her broadest potential and to enjoy a higher quality of life. In this regard, the trust can fulfill needs of not only the beneficiary, but of the parents as well.

Practical Planning/Drafting Considerations

In the process of actually planning the estate, the planner and the parents will confront two major planning issues relating directly to the segregation and management of funds for the benefit of the child:[27]

1. What size trust will be required for the purposes discussed here?

2. Who should serve as the trustee?

None of the literature to date has addressed the questions of the precise funding level to be recommended in the establishement of discretionary spendthrift trusts. This author, with the cooperation of the Washtenaw Association for Retarded Citizens (WARC), has analyzed available information attempting to produce a realistic forecast of need for the beneficiary of such a trust. Much of the information provided by WARC was compiled with reference to its' own experiences as a group home operator.[28]

The estate planner would be prudent in suggesting to his or her clients that they actually record their expenditures in the areas identified below for a period of time (e.g., one year). By so doing, they can assess not only actual needs, but potential areas of special need for their son or daughter. This information can obviously be used to produce the base income required by the trust to meet present need. Once need is established, a corporate trustee will be able to advise both the planner and the client as to the principal required to produce the income needed.[29] (See chart) ▶

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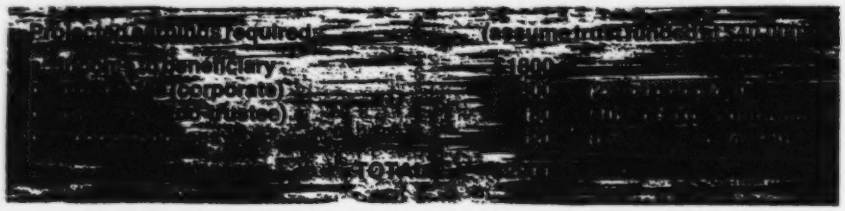
The $1800 figure represents the after-tax net income required to provide for most reasonably forseeable supplemental expenses of a developmentally disabled beneficiary on SSI for one year. The planner, using this figure as a base upon which to build his or her present financial thinking can begin to suggest to his or her clients the general parameters of the size of the allocation that will be required.

There are, however, two additional factors to be considered before the actual amount of allocation is established in the trust document or the will. These include trustees' fees, including administrative expenses incurred in the actual expenditure of funds on the beneficiary's behalf. Additionally, funds should be reserved for accounting fees beyond those normally associated with the preparation of annual tax returns.

There is a possibility that the "throw-back rules" of the Internal Revenue Code could come into play if the trustee is not required to expend all of the income earned annually on behalf of the beneficiary.[30] This author recommends that the decision to expend funds be made solely on the basis of the present need of the beneficiary in the discretion of the trustee(s) in order to avoid "forced" expenditures which might create disqualifying resources.



Since the components of the needs of the beneficiary are identified as $1800 in annual income coupled with the fees of the trustee(s) and a reserve for accounting services, the funding level of the trust can be identified. A survey of several corporate trustees suggests accordingly that in 1983 a trust funded at $40,000 will comfortably produce the income required to meet this need and provide a hedge against inflation.[31]

The total earnings required as illustrated above amount to a very modest 7.25 percent of the corpus of the trust. According to corporate trustees surveyed, funds in the amount of $40,000 placed with them for deposit in 1978 and maintained to present would have yielded earnings in excess of 7.25%. This included sufficient cash income to meet the needs outlined above and growth in the principal value of the corpus sufficient to keep pace with inflation. These trustees considered as certain, the future ability of their companies to meet the income needs of beneficiaries while building the corpus of such trusts at rates commensurate with inflation.[33]

One of the critical issues confronting the estate planner is the proper selection of a trustee to manage the funds so allocated. This process involves answering two separate and distinct questions. First, who should be selected to actually manage the funds held in trust with a view toward proper investment and growth of the funds? Second, who should be selected to manage the funds with a view toward the proper expenditure of the funds in a manner consistent with the purposes for which the trust was established?

Proper management of the funds with a view toward investment and growth requires the skills normally possessed by a corporate trustee. Even at the relatively modest funding levels suggested here, there are significant benefits to be derived from the use of the corporate trustee.

The primary benefit is the "perpetual existence" of the corporate trustee coupled with the insurability of the assets deposited in trust. Often, even where the relatives entrusted with the management of the funds are competent and trustworthy, they are susceptible to their own needs and those of their families. Therefore, brothers and sisters of the handicapped beneficiary are likely to leave the immediate geographic area to pursue their own family obligations or they might become disabled or die, leaving the status of the funds held in trust in an uncertain condition. For these reasons, a corporate trustee is desirable and should be considered in the context of the estate plan.

Experience suggests that trusts of this size are perfectly acceptable to corporate trustees. In testimony on a collateral matter before a state probate court, a vice president of a local trust company recently indicated that he presently had fifteen trusts of a similar size and nature in his portfolio, none of which was presently funded.[34] Indeed, once a planner begins to work with parents of the developmentally disabled, he or she is likely to find that the skills that are required to accurately plan an estate for the parents of the developmentally disabled are in demand throughout the community. Accordingly, a relationship with a local trust company develops relatively quickly as the trust documents are submitted for execution to the selected local trustee.

The planner who can develop or expand an existing relationship with a single trust company provides an additional benefit to the clients. The management of the funds held by the corporate trustee requires particular attention. The trustee cannot, for example, simply place the corpus in a fixed investment vehicle and disburse a check each month or quarter to the beneficiary. As indicated previously, the trustee must exercise absolute discretion with regard to the expenditure of the funds held in trust. Therefore, the trustee should have a working knowledge of the purposes for

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which the trust has been created along with a particular understanding of the needs of the named beneficiary of the trust.

The trustee should be directed to earmark or specifically identify any trust of this nature in his or her files for special attention. The trustee should be encouraged to adopt any coding methods desired which will insure that the beneficiary is identified as developmentally disabled so that expenditures can be monitored accordingly. The planner should consider language in the trust providing the trustee with an outside source of information to which he or she can turn should a question as to the responsibility of the trustee relative to SSI arise in the course of the management of the trust.[35]

Finally, the planner should always consider the use of a co-trustee to address the issue of who should monitor the needs of the beneficiary with a view toward assuring that appropriate expenditures are, in fact, made.

The Role of the Co-Trustee

Without question, family members such as brothers and sisters can be extremely helpful in providing necessary information to the corporate trustee regarding the needs of the specific beneficiary. In fact, the major objection to the use of the corporate trustee would be the "non-relationship" of the corporate trustee to the developmentally disabled beneficiary.

The corporate trustee needs a reliable source of information concerning the needs of the beneficiary as a basis for making the expenditure decisions that he or she will be required to make. In this regard, the aid of a co-trustee can be invaluable to both the corporate trustee as well as to the state of mind of the grantor (parent).

This author recommends that a co-trustee be specifically identified in the trust document and execute the document in the same fashion as the corporate trustee. The purpose of this is to make the co-trustee feel that he or she is an equal party to the original agreement and to identify this party to the corporate trustee as such. Of course, the document will specify the duties of the co-trustee, which are typically limited to advising the corporate trustee with regard to the need for expenditures and monitoring the living conditions of the beneficiary.

Generally, the trust document will specify that the co-trustee will advise the corporate trustee with regard to the need for and the appropriateness of any expenditure. The co-trustee may be given the final authority on the issue of expenditures, according to the wishes of the grantor, but this is not advisable and may not be acceptable to the corporate trustee. The document is clear, however, that the final authority for management of the funds stays with the corporate trustee. The document should also provide that the co-trustee receive a small or no fee for his or her services but that the co-trustee be entitled to be reimbursed for any expenses actually incurred in the performance of his or her duties.

Conclusion

Over the past ten years, the proper approach to estate planning for parents of the developmentally disabled has changed substantially to respond to the emergence of SSI as a basic life support program for the mentally handicapped. Previously drafted estate plans probably require present review in light of these developments.

From the planner's perspective, recent literature suggests that the standard of care in the field requires that the client at least be given the opportunity to consider an estate plan which adequately protects SSI eligibility. Because of the propensity of probate courts to refrain from alteration of written documents evidencing the intent of the settlors of estates, innocent mistakes made by parents in their estate plans precipitated by a lack of knowledge in this area of law can have devastating impact upon the surviving child and his or her brothers, sisters, and other devisees.

The information contained in this article is designed to alert the active estate planner to the particulars of the SSI program and to promote effective estate planning in accordance with present knowledge. In any given case, the estate planner should take steps to insure that the documents drafted will produce the desired results. In the event of uncertainty, the planner should consult a local Association for Retarded Citizens for advice.

For the developmentally disabled, the pattern of deinstitutionalization, family group home life, SSI, and privately funded supplemental trusts, promise an opportunity to achieve many of the comforts and dignities that are available to other citizens of our modern society. Realization of this promise requires knowledgeable planning and careful drafting. The other components are already falling into place. ■

Footnotes

1. The term "developmental disability" means a severe, chronic disability of a person which
   (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
   (B) is manifested before the person attains age twenty-two;
   (C) is likely to continue indefinitely;
   (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and
   (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated. 42 USC 6001 (7).
2. The term "child" refers to an offspring of parents of a developmentally disabled person regardless of whether or not the child has reached the age of majority; the author merely seeks to establish the ordinary relationship between the parent planning his/her estate and the "child" with respect to whom the estate is being planned.
3. This observation is based upon the author's fifteen-year relationship with the developmentally disabled and their parents. Confirmation of this observation has been obtained from the Washtenaw Association for Retarded Citizens, (Ann Arbor, MI) without whose support this article could not have been written.
4. Patrick C. Babcock, Director of the Michigan Department of Mental Health, in testimony in an unrelated civil matter stated that in 1983, the Department of Mental Health would place "between 900 and 1200 people" — in group homes, a number that has remained at a fairly constant level since 1981. (Deposition of Patrick C. Babcock, 83-8602, In the Court of Claims at page 10).
5. Per diem costs vary for developmentally disabled individuals depending primarily on the nature of medical support services required. The cost of community placement in Michigan ranges from $9.90/day for a person on general assistance to $176/day for certain AIS home residents. The per diem cost for a person in a state institution or similiar facility ranges from $92/day to $194/day. On the average it is more economically advantageous to have persons living in the community. (source: Washtenaw Association for Retarded Citizens, based upon statistics supplied by the Michigan Department of Mental Health).

6. This conclusion is stated with varying degrees of certainty by virtually all authors from Lawrence A. Frolik, "Estate Planning for Parents of Mentally Disabled Children," 40 *University of Pittsburgh Law Review*, 305 (1979) to Judith C. Mero, Estate Planning for Families With a Disabled Child," *The Estates, Gifts & Trusts Journal*, March-April, 1983.
7. Whaley v Schweiker, 663 F2d 871 (1981). see 42 U.S.C. 1381.
8. Frolik, supra note 6, at 316.
9. PROGRAM OPERATIONS MANUAL SYSTEM (POMS), Supplemental Security Income, June, 1983, U.S. Department of Health and Human Services, Social Security Administration, SI 00810.010 — Income for SSI Purposes. (POMS is the operations manual for the Social Security Administration and is used by its personnel in processing SSI applications).
10. Frolik, supra note 6, at 317.
11. Interview with Dohn Hoyle, Executive Director, Washtenaw Association for Retarded Citizens, (WARC), Ann Arbor, on September 20, 1983. WARC operates 6 group living facilities and one apartment project for developmentally disabled individuals throughout Washtenaw County.
12. 42 U.S.C. 1396, the Medical Assistance Program (MEDICAID) is a federal-state partnership administered by the states.
13. "MEDICAID/CARE . . . which is which?", Health Care Financing Administration, United States Department of Health and Human Services, HCFA-02129, 1980.
14. Ibid at 15.
15. Ibid at 15.
16. Hoyle, interview supra note 11.
17. PROGRAM OPERATIONS MANUAL SYSTEM (POMS), July, 1983, SI 01110.001 A. Resource Limitations.
18. Ibid, SI 01110.010 Resources Defined.
19. 42 USC 1382 (1983).
20. Ibid.
21. 20 C.F.R. 416.1102 (1983).
22. 20 C.F.R. 416.1131(a) (1983).
23. Interview with Marsha Katz Johnson, Financial Specialist/Services Advocate, Family Resource Center, Washtenaw Association for Retarded Citizens, July 14, 1983.
24. POMS, sec 12520(2) Beneficiary, 1979.

    "If the claimant/beneficiary's access to the trust principal is restricted (e.g., only the trustee or court, etc., can invade the principal), the principal does not count as a resource to the claimant."
25. Ibid.
26. Ibid. sec 12520 (b) provides that: "(1) If the claimant/beneficiary has a right to the income from the principal of the trust as it becomes available (whether or not it is applied for his use on a current basis), it is income to him as it become available. [See sec 12307 (a).]"
27. The federal and state estate and/or gift tax consequences of the estate plan, as well as collateral issues concerning marital trusts and the like are beyond the scope of this discussion and not considered by the author.
28. Research conducted during the spring of 1983 and based upon an analysis of WARC homes, apartments, and supervised independent living arrangements.
29. The analysis suggested is to plan as though an annuity were being purchased requiring income at the particular level; funding therefore to "present" need with an adjustment for short term future inflation. Clearly the amount of the bequest to the trust can be modified by the parents in the future so that during their lifetimes the trust is never underfunded to present need.
30. IRC sections 661-665.
31. Sources: Ronald Gardner, Trust Officer and Vice President, Ann Arbor Trust Company, Ann Arbor; William Groth, Trust Officer and Vice President, 2nd National Bank, Hamilton, Ohio.
32. While fees vary, the fee recited here considers a fixed charge against principal and 1% of income earned, and is probably overstated.
33. Gardner, Groth, supra note 30.
34. Testimony of Ronald Gardner, *In Re* (name omitted), Probate Court, Washtenaw County, October, 1983.
35. e.g., "The Washtenaw Association has or will be appointing a person with whom the trustee shall/may consult in the event of a question concerning the advisability of any particular expenditure relative to eligibility for pertinent government programs."

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